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Poster P30

ACMT-Rete: A Patient-Led Network Integrating Research, Awareness, and Community for Charcot-Marie-Tooth

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ACMT-Rete is Italy's patient-driven association for Charcot-Marie-Tooth (CMT), a progressive inherited neuropathy. Our mission is to build a collaborative "Rete" (Network) that unites patients, clinicians, and researchers to accelerate progress and provide holistic support.

We fund patient-centric research, like the 2024 project led by Dr. Yuri Matteo Falzone (University of Milan). His work investigates the complex mechanisms of balance deficits in CMT, aiming to develop targeted, more effective rehabilitation protocols to improve stability and reduce fall risk.

To demystify stigma and raise public awareness, we support innovative outreach like "The Ballad of Human Mutations", a unique art installation that translates CMT hands and feet into pieces of artwork with an engaging narrative about the importance of diversity.

Our fundraising is rooted in community. The "Bottoni che Fatica" (Button Jewelry) project transforms donated buttons into handcrafted pieces, symbolizing how our community creates value to directly fuel research.

Recognizing the unique challenges faced by youth, we launched "Generazione Z: Crescere con la CMT" (Generation Z: Growing up with CMT). This vital project provides dedicated support and a peer network for adolescents and young adults navigating the transition to adulthood with a chronic condition.

By integrating targeted research, creative awareness, grassroots fundraising, and peer support, ACMT-Rete fosters a holistic ecosystem that empowers patients and drives meaningful change in the fight against CMT.